



SPINAL COURIER

SPINAL CORD
COMMISSION

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Bigger and Better!

On May 1-2, 1998, the Arkansas Spinal Cord Commission (ASCC) will proudly host its eighth annual conference, and its first on a regional level. Entitled *Living with Spinal Cord Disability: Strategies for the New Century*, the conference will be held at the Double-Tree Hotel in downtown Little Rock. This conference marks a change from the format of previous conferences. It has been expanded from one day to two days and the program will offer a greater variety of topics and includes speakers from a number of other states.

Mark Wellman will open the morning session on May 1 with the keynote address. Wellman, who lives with paraplegia from a fall, achieved national fame by climbing two of the most challenging mountain peaks in the United States: El Capitan and Half Dome. He has also written his autobiography, *Climbing Back*, in which he states "there is almost no limit to what we can accomplish — except perhaps in our own minds."

Other sessions will include topics on pain management, recreation, nutrition, home modifications and

alternative health options. Exhibitors will be on hand to demonstrate new equipment and to answer your questions about their products and services. Besides the many educational opportunities, there will also be time to meet old friends and make new ones. It will be two days of fun and learning that you won't want to miss!

Registration brochures will be mailed in February, so return your registration form early (scholarships will be available to ASCC clients and their family/providers). If you have questions about the conference or registration, please contact **John Gould** at **501-296-1784** or **1-800-459-1517**. &

Sharon Martin Joins ASCC Staff

Sharon Martin, MNSc, RNP has joined the ASCC staff as Project Coordinator for the CAPPS (Consumer Action to Prevent Pressure Sores) project. Sharon brings a wealth of knowledge, experience and enthusiasm to the Commission and her new position. She has worked in acute rehabilitation, critical care and long-term care and, most recently, she taught at the Baptist Schools of Nursing and Allied Health. Some of you may remember Sharon, as she is actually returning to the Commission. She worked here in 1989-90 on another pressure sore prevention project.

Sharon, working out of the Little Rock office, will be coordinating the CAPPS project in 13 south Arkansas counties over the next



ASCC welcomes Sharon Martin, Project Coordinator for the CAPPS project.

three years. She jumped into the project quickly, and has already met with members of her Consumer Advisory Committee around
Continued on page 5 - see "Sharon Martin"

Van Give Away

Finding accessible transportation is a significant problem for many individuals with disabilities according to numerous studies in Arkansas and the nation. The cost is significant, not only to obtain the vehicle and have it modified, but also to maintain it. Few resources exist to help people with these costs, but, occasionally wishes come true.

Christmas came early for **Hal West** of Pine Bluff who was selected to receive a van donated to the Commission. The van was donated by former ASCC Commission member **Grover Evans**. Evans had purchased a new van recently, and wanted to share his

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SPINAL COURIER

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BUCKLE UP!

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Internet Access Available

Dear Editor:

I would like to say thank you to all of the people who responded to the survey about the ASCC's new web page. A number of people sent in great ideas and we are going to be incorporating many of them into our web page.

In addition, a few people brought up a very valid point. Many people do not have computers or their computers are not connected to the internet. But there are still ways

to use the internet. Many public libraries in Arkansas have computers for public use. All libraries in the Central Arkansas Library System, North Little Rock and Conway County have computers connected to the internet for public use. Some of the libraries in Faulkner County and the Mid-Arkansas Regional Library System are also connected. And, libraries in White County are currently working on getting internet access for the public.

So, if you want to find something on the internet, give your local library a call because they may be able to help.

*Jenni Friedberg, VISTA
AR Education & Resource Center*

From the Director

Words are funny things — the same word can bring to mind so many different images. Take the word "depend." None of us want to be dependent. In fact, most of us strive to be the opposite — independent! But I think most of us appreciate someone we can "depend on" — that person who is there for us, through thick and thin, good times and bad. Someone who will "be there" even when we aren't our very best selves.

This has been an interesting year for me, in that those folks I can depend on are changing. This month Dr. **Shirley McCluer** is retiring from the Commission. The first day I came to ASCC as a new Case Manager, Dr. McCluer took me under her wing and we became fast friends. Over these 10 plus years, she has been the one who was there to listen to my dreams and plans and to my failings and disappointments. I can always trust that she will be honest and straightforward in her assessment and her support. She regularly reminds me of what we have accomplished, when I'm looking at all that is yet to be done. Besides her experience and expertise, she has shared herself with me and our Commission. We have become good traveling companions (take it from me, she can get you around Disney World in no time flat!). Shirley McCluer is someone I can depend on. I will miss her.

Another stalwart pal is also "retiring" this month. **Virginia Crookston** is leaving the Spina Bifida Association board this month. In her tenure with SBAA, Virginia has been Executive Director, Secretary, Newsletter Editor — basically, Virginia has been the person who "got things done" for the past eight years. Virginia and her husband Jim have worked tirelessly for folks with spina bifida in our state and certainly are ready to enjoy their retirement! Thanks, Virginia !!!

Here's to 1998 — I hope it brings you joy, independence and folks you can depend on! See you at the conference in May.

Cheryl L. Vines

With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at (501) 296-1788 / (800) 459-1517 / TDD (501) 296-1794 or send your donation to:

AR Spinal Cord Commission
1501 North University, Suite 470
Little Rock, AR 72207

Donations this quarter from:

*Jimmy Ashley
Mr. & Mrs. Romonlol Bhakta
Grover Evans
Paul Johnson
Wayne Phillips*

Shirley McCluer Retires

Dr. Shirley McCluer, Medical Director of the Arkansas Spinal Cord Commission since 1985, retired on December 31, 1997. Dr. McCluer has been integral in the Commission since its inception, working closely with founding Commission member Jane Smith in identifying the needs of Arkansans with spinal cord disabilities while she was Medical Director at the Hot Springs Rehabilitation Center in the 1960's. Dr. McCluer is the Commission's second Medical Director, following Dr. Steve Flanigan's tenure.

Dr. McCluer has practiced medicine since 1954. She is a Board Certified Physiatrist and has specialized in spinal cord injury (SCI) care and treatment for most of her career, which has taken her all over the United States and Europe working in SCI Centers and treating thousands of individuals with SCI.

The Commission was lucky. When she retired from practice in 1988 and from the UAMS Department of Physical Medicine in 1991, Dr. McCluer agreed to stay on at the Commission. She has been integral in the development of numerous research and grant projects, the development of agency policies and procedures and is the inventor of the ASCC *Autonomic Dysreflexia Medical Alert Card*. She is the "mother" of the ASCC fact sheet series and has



Dr. Shirley McCluer accepts a plaque recognizing her years of service to ASCC as Medical Director from Commission President Russell Patton on December 4, 1997.

personally written the majority of them, including a recent one on the history of the agency.

Often referred to as "our own Dr. Ruth," Dr. McCluer has been tireless in her efforts to train our Case Managers to assist their clients in managing their medical care and has always been willing to provide her insights and recommendations when a client or family member calls.

Though she is formally retiring, still expect to see her around. Dr. McCluer will be a speaker at our

May conference reporting on her latest "passion" — acupuncture treatment of pain in persons with SCI. (*See related article on page 5.*) Commenting on her plans for retirement, Dr. McCluer said, "This will give me more freedom to travel and to pursue my interest in genealogy."

Everyone at ASCC agrees with the plaque presented to Dr. McCluer by the members of the Commission at the December meeting which reads, "Though you are retiring, the legacy of your work here will continue." ♪

1997 ASCIA Scholarships Announced

The Arkansas Spinal Cord Injury Association (ASCIA) has announced the two recipients for their 1997 scholarships. Scholarships were presented to **Kimberly Myles** of Osceola and **Mike Morrissey** of Little Rock.

Kimberly is a student at Mississippi County Community College in Blytheville studying Elementary Education. Mike is a graduate student in Rhetoric and Writing at University of Arkansas at Little Rock.

Since 1993, ASCIA has presented twenty-one scholarships, totaling over \$10,000, to Arkansans with spinal cord disabilities throughout the state.

Time to Apply for Scholarships for Fall

Arkansas Governor's Commission on People with Disabilities

Deadline - April 15, 1998

Eligibility: Any disabled person in the state who will be attending a college or university or vocational-technical school is eligible to apply for a scholarship through this office. Students awarded scholarships will be required to take 12 hours per semester unless disability prevents them from taking a full load. Partial scholarships may be

available to part time students.

GO FOR IT!

Guidelines: Must have documentation of disability, a completed application form, a letter

from an official at the school you have chosen to confirm that you have been accepted there for the fall semester, a letter of recommendation from an adult who can testify to your academic abilities and personal character (evaluator cannot be your relative) and a letter of recommendation from a professional who has knowledge about the extent of your disability, such as a rehab counselor, therapist, psychologist, etc. (may not be your relative).

You may request a scholarship application packet by calling **501-296-1626** (voice) or **501-296-1672** (TDD).

Spina Bifida Associations Scholarships

Deadlines - June 15, 1998 (local) / April 15, 1998 (national)

Eligibility: Persons with spina bifida who will be attending a college, university or vocational-technical school may apply for local and national spina bifida scholarships. Past recipients may apply, however first consideration will be given to those who have not previously received a scholarship.

Guidelines: Must have spina bifida, reside in Arkansas, have been accepted to a school for the fall semester of 1998 and must complete an application that includes a written essay, proof of acceptance or registration for fall and a letter of recommendation.

To receive applications for both local and national organizations' scholarships, call **501-978-7222**. &

Van Give Away

Continued from page 1

good fortune by passing his older van on to a person who could use it. Evans was anxious that the recipient be someone who could drive the van and use it to go to work or school. He asked the Commission to assist him in finding a recipient. Commission members reviewed applications from 33 individuals at their December 4 meeting and, after careful deliberation, selected Hal West.

Hal has lived with quadriplegia since 1973 and has worked for the Social Security Administration since 1980. For much of that time, he has been dependent on others to get to work, sometimes missing work when he had no transportation.

ASCC Executive Director Cheryl Vines and Pine Bluff Case Manager Bobby Johnson made the presentation of the 1988 Ford



ASCC Pine Bluff Case Manager Bobby Johnson (left) and ASCC Executive Director Cheryl Vines (right) presented the donated fully wheelchair accessible van to Hal West (center) of Pine Bluff on December 17, 1997.

van to Hal on Wednesday, December 17. "I never win anything," said Hal, who had taken a "wait and see" approach when he was informed that he had been selected to receive the van. "It's like it was made for me. I don't have to duck my head to get in

and I can move around. This is just amazing!" exclaimed Hal.

The Commission congratulates Hal and is very happy to have assisted in this recent van give away. &

Acupuncture and Spinal Cord Injury

By Shirley McCluer, M.D., ASCC Medical Director

Several months ago I asked for anyone who has had any experience with acupuncture for problems related to their spinal cord injury (SCI) to contact me about their experience. I had only two or three responses, but I know there are probably more of you out there. I still want to hear from anyone who has information — either positive or negative.

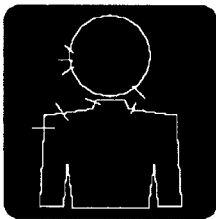
I have been very interested in acupuncture for a long time. In 1980, I visited China and observed, among other things, an open knee operation with acupuncture as the only anesthesia. I saw many other situations where it was clearly useful. Since then, I have watched for any evidence that acupuncture might be useful in SCI, but only heard an occasional report that was not very convincing. I kept assuming that someone else would try it and report the results. Unfortunately, I have not seen anything in the medical literature about successful treatment until 1995 when a Canadian physician reported excellent results treating SCI pain with acupuncture at our national SCI meeting. Spinal cord pain is a major problem for some individuals and response is poor to most conventional therapy, so I was quite excited about the possibilities.

In October, 1997, I visited the Spinal Cord Injury Hospital in Toronto, Canada where they were treating spinal cord pain with acupuncture. I was very impressed by what I saw and heard on the trip. Since my return, I have been contacting Arkansas physicians and acupuncturists to work out a program where we can try some of the techniques here. I have already located several physicians in Arkansas who are certified in acupuncture and who are interested in trying the techniques used in Toronto. The procedure is very simple, so

we should soon find out how well it works. I had hoped to have a plan to report to you by this time, but unfortunately all of the details have not been worked out. All ASCC Case Managers will be kept up-to-date on any plans that are made. If you are interested in participating, please contact your Case Manager and ask him or her to keep you informed about this project.

Physicians in general have difficulty accepting the idea of acupuncture because the theories of what is done and why it works do not fit into the scientific medical approach to disease. Communication between physicians and acupuncturists is almost impossible. It is like they are speaking two completely different languages and neither understands the other. However, in recent years more physicians have taken special training in acupuncture and have become certified in Medical Acupuncture (including several in Arkansas). Most of them use it in the treatment of pain because of the sometimes dramatic results in individuals who had failed to improve after extensive conventional medical care.

Because of the continued reports of good results from acupuncture in a variety of diseases or symptoms, the National Institutes of Health (NIH), one of the most prestigious medical research organizations in the United States, sponsored a three day conference in November, 1997, to discuss acupuncture. A panel of experts from all over the world gave testimony about what is currently known or believed about this form of treatment. A "Consensus Statement" was developed by the conference members at the end of the conference. (A



copy of the entire statement can be obtained from the Resource Center of the Spinal Cord Commission — request the *NIH Consensus Statement on Acupuncture*.) In summary, the report says that "there is sufficient evidence of acupuncture's value to expand its use into conventional medicine and to encourage further studies of its physiology and clinical value." This is what we hope to do.

For more information about acupuncture in general, anyone with access to the Internet is referred to: <http://www.MedicalAcupuncture.org>

Reminder — please call me at 501-296-1788 or write me at the Commission about any acupuncture experience you have had. ♪

Sharon Martin

Continued from page 1

the state to assure their insights and input are included from the beginning of the project. "This is a very exciting project that will provide valuable information and address a major concern of ASCC clients. I am thrilled to be a part of it!" stated Sharon.

Sharon is a native of Wynne, AR and she lives in Little Rock with three of her four sons (yes, she is a busy lady). When she has free time she enjoys sewing, crocheting, reading, cooking (old-fashion Southern style) and is an avid supporter of her sons' football and baseball activities.

Please join the Commission members and staff in welcoming Sharon to our staff! ♪

Alyssa Dillavou Chosen as Star Child for UCP Starfest '98

The 1998 United Cerebral Palsy Starfest on KATV, Channel 7, featured three year old Alyssa Dillavou, an ASCC client and student at the UCP Butterfly Learning Center. Hosts for the event were **Dwayne Graham**, **Steve Powell** and **Meghan Stone** of Channel 7 and **Todd Hickingbotham** at the Butterfly Learning Center.

Born with spina bifida, Alyssa has learned to look at her abilities, not her disabilities, and to develop her skills. She has learned to walk with a walker and, through the individualized attention provided by therapists, has developed an extensive



Three year old Alyssa Dillavou was featured on UCP's Starfest 1998.

vocabulary and is able to carry on conversations with adults. Starfest, aired live on January 11,

1998, is in its nineteenth year on television. It provides an opportunity for viewers to pledge their financial support to help provide services and programs for physically and mentally challenged Arkansans. The national segments of the show featured well-known entertainers and sports stars.

UCP's Starfest not only helps to raise funds, but also offers an opportunity for the public to learn about the services provided by United Cerebral Palsy. Special features each year are seeing UCP clients, like Alyssa, who have turned challenges into triumphs. ♪

Fort Smith Mini-Conference a Huge Success

The Arkansas Spinal Cord Commission's latest mini-conference, *Spinal Cord Injury: An Update*, was a huge success. The conference was held at HealthSouth Rehabilitation Hospital in Fort Smith on October 15, 1997. Highlights of the mini-conference included:

- ASCC Executive Director **Cheryl Vines'** presentation, *Aging and Arkansans with SCI*, discussed the research findings on the secondary conditions that affect those with spinal cord disabilities. Race, income level and education were all correlated to the incidence of secondary conditions as people age.
- *The Independent Living Movement and Model of Providing Services* was presented by **Scott Marlow**, an Independent Living Specialist for SOURCES, who lives with SCI. Mr. Marlow provided an overview of how the

Independent Living Movement has blossomed and what it means to those living with SCI.

- *Pain Management and Spinal Cord Injury* was presented by **Carl Covey, MD**, a practicing physician at the Little Rock Pain Clinic. Dr. Covey's presentation discussed various types of pain and possible treatments.
- *New Options in Bladder Management for SCI* was presented by **Alex Finkbeiner, MD**. His discussion covered the many types of urine collection devices. He stressed the need for doctors and patients to understand that when using a foley or intermittent catheter, bacteria is expected to be present in the bladder and, unless there are other symptoms such as a fever, the person should not be treated for an infection.

- **Dr. R. Cole Goldman's** discussion of *Pressure Sore Closure Surgery and Its Implication* was accentuated by the use of graphic slides to show views of pressure sores before and after the surgery.

This mini-conference was packed full of useful information for people living with SCI and professionals alike. ♪

Attention Teen Wheelchair Users!

"Spring Forward" is a therapeutic support group for teen wheelchair users. This group will address some of the special challenges teens face, such as issues of independence, peer and academic pressures, family life, depression and decision making. For more information, call **501-227-7044**.

Support Groups Online

There are a number of groups that can be accessed through home computers. America Online offers the following which should be of interest to persons with spinal cord disabilities:

Mondays 10:00 am

MS Room: Equal Access Cafe.
Keyword: Dis>Chat Rooms
button

Tuesdays 5:00 pm

MS Gals (for women only).
Keyword: Better Health>Events
button

Wednesdays 7:00 pm

SCI Support Group Room: Mutual Support Lounge. Keyword: Better Health>Events button

Wednesdays 5:00 pm

MS and Alternative Medicine.
Keyword: Better Health>Events
button

Wednesdays 6:00 pm

Newly Diagnosed MS Patients.
Keyword: Better Health> Events
button

Saturdays 9:00 pm

SCI Support Group
Room: Equal Access Cafe.
Keyword: Dis>Chat Rooms
button

Information on spinal cord injury can be found on the Internet at the following address:

<http://www.sci.rehabm.uab.edu>

Electric Hospital Bed Malfunctions

Ever had your electric hospital bed just stop working or work intermittently? Here are a few things you can check yourself that might save you the cost of a maintenance call.

1. Check to make sure that the bed is plugged in at the electrical outlet.
2. Check for a loose electrical plug at the outlet.
3. Check for a loose electrical plug or plugs under the bed.
4. Check for the block out switch at the end of the bed; it may have been accidentally turned off.
5. Check for a pinched or broken wire under the bed.

Items one through four can be "fixed" without professional help. However, you may want to have a

professional repair broken wires and check for other short circuits.

Here's another hint you may find helpful: when the electric bed has reached its maximum or minimum position, **stop pushing the button!** Otherwise, you will have to press on the reverse button an equal amount of time before the bed will start to move again in the opposite direction. If you continue to press on the button and then go in the opposite direction, the bed will make a humming noise and will not move until the gears catch up to their normal starting point. Often this humming noise and lack of movement is thought to be a malfunction, when in fact the operator just had a heavy thumb!

Thanks to ASCC Case Manager Robert Griffin, Mike Eden of G & G Medical Supply and Steve Seacres of Alliance Homecare for this helpful information. &

Junior Rollin' Razorbacks Update

The Arkansas Junior Rollin' Razorbacks hosted the MidSouth Regionals American Healthcare Providers Healthfest Championship on November 14-16, 1997, in Hot Springs where they placed fifth in the 10 Foot Division and third in the 8 1/2 Foot Division. **Ryan Buchman** was picked the Tournament MVP and **Todd Crowe** the All-Tournament Defensive Player. In the 8 1/2 Foot Division **Tyler Garner** was Tournament MVP, **Justin Crawford** the All Tournament Offensive Player and **Jason Allen** and **Justin Brown** were picked All Tournament Defensive Players.

At the Texas Regionals held in Dallas on November 22-23, 1997, the Junior Rollin' Razorbacks took third place in the 10 Foot Division. Ryan Buchman was selected to the All-Tournament Team. In the 8 1/2 Foot Division the team finished second. Tyler Garner was picked the Division MVP. &

Quad Rugby Players Needed

The Arkansas Quad Hogs are trying to put a team together for the 1998-99 rugby season. The Hogs practiced last year in Fort Smith, Arkansas, but due to lack of players the team separated. This year they want to try again. Practices will begin in September in both Fort Smith and Little Rock. The actual season will start in December. All quads interested in playing rugby should contact **Randy Alexander** at 501-570-5257 or e-mail RandyA@aristotle.net

Check Out the New Resources!

Throughout the last few months, ASCC has been very busy trying to update resources in the Arkansas Education and Resource Center. Besides updating all of the catalogs, current information has been obtained on regeneration, pain management (including a great article from *Pushin' On* that comes highly recommended by Cheryl Vines and Dr. McCluer) and Post-Polio Syndrome. Plus, the Resource Center has gotten a number of great new resources.

- ***The Accessible Housing File*** by *Barrier Free Environments* is a useful collection of accessible designs which can be unobtrusively included into new housing or used for remodeling.
- ***The Resource Guide for Developing Policies on Children with Special Health Care Needs*** is a new guide for educators, parents and health providers that will aid in the development of school district policies that ensure a quality education for students with special health care needs.
- ***You're Not Alone*** book and video offer inspirational life stories from 38 amputees, while providing information on prosthetics.
- ***Sexual Rehabilitation of the Spinal Cord Injured Patient***, edited by J.F.J. Leyson, MD. While this book provides comprehensive coverage of sexuality in disabled persons, it has an additional focus on the psychosocial aspects of sexuality.
- ***FES Resource Guide*** describes what functional electrical stimulation (FES) is, its possible benefits for people with SCI and multiple sclerosis and gives other resources on FES.
- ***Don't Worry, It Won't Happen to Me*** video and study guide is a prevention program intended for middle and high school students. Created by the Frazier Rehab Center, the video uses students to teach students about the things they can do to prevent spinal cord injuries.
- ***The Quest for Cure*** by Sam Maddox contains information on the ongoing efforts to cure spinal cord disabilities, including research into regeneration and transplants.
- ***Starting Over*** video series. This series of four short videos covers skin care, autonomic dysreflexia, bowel care and diet and medication.
- ***The ASCC El Dorado Mini-Conference***. All of this informative mini-conference's sessions were videotaped. Topics covered include bowel and bladder management, stress management, living with SCI and the ADA.

If you are interested in checking out any of these resources or are looking for information on another topic, please visit the Arkansas Education and Resource Center on Spinal Cord Injury in Little Rock or call **Jenni Friedberg** at **501-296-1792**. ☺

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